A community-based primary care “medical home” is a health care practice in your community that is completely responsive to you and your child’s needs. This is especially so when your child has a chronic health condition or disability. A group at the Hood Center for Children and Families at Children’s Hospital at Dartmouth Hitchcock Medical Center (New Hampshire) has been asked to create a Medical Home Index to find out about the medical “homeness” of a health care practice or office.

Your child’s primary care provider fills out The Medical Home Index; this set of questions looks at the care activities that make the medical home “come alive” in practice. Health care providers will rate the care that they offer to children with special health care needs and their families. They will comment on how they partner with families in their children’s care and provide care coordination and other needed supports.

No questionnaire truly captures the medical “homeness” of a practice unless information is gathered from families. You are being asked to fill out this Medical Home Family Index and to report on the services and supports that your child actually receives. The Medical Home Family Index uses twenty-five questions to capture the family perspective, please try to answer each question to the best of your ability. Thank-you for your willingness to complete this set of questions and for your thoughtful comments written at its end.

Please turn to the next page . . .
## THE MEDICAL HOME FAMILY INDEX:
Measuring the Organization and Delivery of Primary Care For Children with Special Health Care Needs

The following questions refer to the care that your child receives from his/her pediatrician or primary care provider (PCP) and the staff who work in their office. Next to each question circle the response that best describes your experience of care for your child.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Through this practice/office I can get the health care that my child needs when we need it (including after office hours, on weekends and holidays).</td>
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<tr>
<td>2. When I call the office: (please answer for a, b, c, and d):</td>
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<tr>
<td>a) Staff know who we are</td>
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<td>b) Staff respect our needs and requests</td>
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<td>c) Staff remember any special needs or supports that we have asked for</td>
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<td>d) We are asked if there are any new needs requiring attention</td>
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<td>3. My primary care provider (PCP) uses helpful ways to communicate (e.g. explaining terms clearly, helping us prepare for visits, e-mail, or encouraging our questions):</td>
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<tr>
<td>a) With me</td>
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<tr>
<td>b) With my child (If (b) does not apply to your child ✔ here ___)</td>
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<td>4. My PCP asks me to share with him/her my knowledge and expertise as the parent or caregiver of a child with special health care needs (CShCN).</td>
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<td>5. I am asked by our PCP how my child’s condition affects our family (e.g. the impact on siblings, the time my child’s care takes, lost sleep, extra expenses, etc.).</td>
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<td>6. My PCP listens to my concerns and questions?</td>
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<td>7. Planning of care for my child includes: (please answer for a, b, c and d):</td>
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<tr>
<td>a) The writing down of key information (e.g. recommendations, treatments, phone #)</td>
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<td>b) Setting short team goals (e.g. for the next three months)</td>
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<td>c) Setting long term goals (e.g. for the next year or more)</td>
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<td>d) Thorough follow-up with plans created</td>
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<tr>
<td>8. My primary care provider and staff work with our family to create a written care plan for my child. (If your answer is “never”, then skip to Question # 11)</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
<td>Always</td>
</tr>
<tr>
<td>Question</td>
<td>Never</td>
<td>Sometimes</td>
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<td>Always</td>
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<td>9. I receive a copy of my child's care plan with all updates and changes.</td>
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<td>10. My primary care provider (PCP) and his/her office staff (please answer a, b and c):</td>
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<tr>
<td>a) Use and follow through with care plans they have created</td>
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<td>b) Use a care plan to help follow my child's progress</td>
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<tr>
<td>c) Review and update the care plan with me regularly</td>
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<tr>
<td>11. My PCP has a staff person(s) or a “care coordinator” who will:</td>
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<tr>
<td>a) Help me with difficult referrals, payment issues, and follow-up activities</td>
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<td>b) Help to find needed services (e.g. transportation, durable equipment or home care)</td>
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<td>c) Make sure that the planning of care meets my child and my families needs</td>
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<td>d) Help each person involved in my child's care to communicate with each other</td>
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<td>(with my consent).</td>
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<tr>
<td>12. When or if I ask for it, our PCP or office staff help me to:</td>
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<tr>
<td>a) Explain my child's needs to other health professionals</td>
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<tr>
<td>b) Get my child's school, early care providers or others to understand his/her condition</td>
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<tr>
<td>(If (b) does not apply to your child ✔ here ___)</td>
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<tr>
<td>13. Someone at the office is available to review my child's medical record with me when or if I ask to see it.</td>
<td>Yes</td>
<td></td>
<td>No</td>
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<tr>
<td>14. Office providers or staff who are involved with my child's care know about their condition, history, and our concerns and priorities.</td>
<td>Yes</td>
<td></td>
<td>No</td>
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<tr>
<td>15. My PCP or his/her office staff sponsor activities to support my family (e.g. support groups, parent skill building or how to support other parents).</td>
<td>Yes</td>
<td></td>
<td>No</td>
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<tr>
<td>16. Office staff help me to connect with family support organizations and informational resources in our community and state.</td>
<td>Yes</td>
<td></td>
<td>No</td>
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<tr>
<td>17. My PCP is a strong advocate for the rights and services important to children with special health care needs and their families.</td>
<td>Yes</td>
<td></td>
<td>No</td>
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<tr>
<td>18. My PCP assists me in finding adult health care services for my child. (Check here if due to your child's age this does not apply ____).</td>
<td>Yes</td>
<td></td>
<td>No</td>
<td></td>
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</tbody>
</table>
Would you please go back over this Family Index to check for unanswered questions; try to answer them to the best of your ability.

Please write down:

The name of the practice where you go for your child's care: ______________________________________

The name of your child's primary care provider: ________________________________________________

The length of time your child has been cared for by this practice? _____________________________

Your name, address, & social security #: ____________________________________________________

Address: ____________________________________________ SS# __________________

(Optional) What is the racial/ethnic background with which you most closely identify?

☐ White, Non-Hispanic ☐ African American ☐ Hispanic ☐ Native American/American Indian/Alaskan Native ☐ Asian ☐ Other (specify)

May we have your permission to contact you further about this project? ☐ Yes ☐ No

Other comments you would like to make? (Feel free to use the other side) ____________________________

Thank You for Sharing Your Experiences